

IDAHO CHAPTER

NATIONAL HEMOPHILIA FOUNDATION

NEWSLETTER

VISION STATEMENT

The Idaho Chapter of NHF envisions a united community that will make a positive difference in the lives of individuals affected by a bleeding disorder.

Education: within and outside the bleeding disorders community.

Advocation: at local, state, and national levels.

Inclusion: of family, friends, and all those impacted by the disorders.

Development: of a legacy for a future of hope.

FROM THE DIRECTOR

Grateful. As we near the end of 2020, one tends to reflect on the accomplishments and experiences from early in the year... and we all know that 2020 has been quite unique. Even through it all, I am grateful for this community and the experience we were able to have. December 10 marked my 1-year work-iversary. Having the better part of your first year in a role during a pandemic is far from ideal, but I did it. Thank you for supporting me and the chapter this year through attending events, interacting with us on social media, fund raising, and having phone/email conversations with us. Your involvement helps shape our community and its programs.

These last few months have been full of events—we celebrated and provided programming for our von Willebrand Disease Community; we banded together and raised money through our Unite for Bleeding Disorders Walk fund raiser; we joked and laughed, had some serious conversations, and made new friends through our educational sessions; and had A LOT of fun at our Holiday Party.

I want to highlight a pilot program that we were recently awarded a grant to create. We have teamed up with a counseling center to provide tele-health counseling services for our rural community members. Now, more than ever, it is important that we stay connected and aware of our mental health. So, if you live in town or in the country and could benefit from counseling services please contact me, mkrieger@hemophilia.org or 208.344.4476 and I will send you the information.

As we close 2020 and prepare for 2021, I encourage you to take the time and participate in a few surveys. These surveys were designed to better our community. One is at the national-level supported by the National Hemophilia Foundation—Community Voices in Research (CVR). The other is specific to our chapter—Needs Assessment—to allow us to best support you. Both surveys provide vital information to our chapter that, in turn, will be used to inform decision and programing efforts put forth by the chapter. More details about the surveys can be found in this newsletter.

I would like to also thank our volunteers, board members, and Marlyn for a great year—thank you for all the time and energy you put into this organization to make all the events and activities happen.

Happy Holidays and a Happy New Year!

Michael Krieger, Executive Director

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OUR CHAPTER

NHF Idaho is fortunate to be guided by an enthusiastic, talented, and hard working group of people.

Board of Directors

Walter Justus, *Acting President*

Joe Rex

Michelle Weickum

Office Staff

Executive Director

Michael Krieger

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Marlyn Walker

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Address

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idahoblood.org

Board Help Wanted

The NHF Idaho Chapter is looking for additional members to serve on our Board of Directors. If you, or someone you know, might like to serve our bleeding disorders community by being on our board, please let us know. To add balance to the board we would be especially interested in talking to folks outside of the bleeding disorders community.

To learn more about this opportunity to serve, please call the Chapter office.

208-344-4476



This year, we added a few twists to our typical Walk program. Since we only held one walk and it was virtual in October, we were able to create fun interactions leading up to the Walk. This year we "United for Idaho" and spent 6 weeks traveling to different destinations within Idaho. On our walk day, we were able to connect, have some fun, spin the prize wheel, unveil our fund raising accomplishments, have our walk ceremony, and kick off our virtual walk. We were blessed by our amazing community members and sponsors that supported our fund raising efforts.

We raised just over \$18,000!

We would also like to thank our Unite for Bleeding Disorders Walk Sponsors:

National Sponsors

Presenting: Takeda

Official: Bayer, Sanofi Genzyme,

Optum, Grifols

Partner: Accredo

Local Sponsors

Silver: CSL Behring, Genentech

Friendship: CVS Specialty,

Octapharma, St. Luke's

Top Team Captain

Kyla Krieger

Top Teams

Team Sir Huxley

The Red Comets

JUSTUS for ALL

Myers' Tribe

9 Guy's Family & Friends

Top Fund raisers

(eligible for an incentive)

Michael Krieger*

Kyla Krieger*

Danny Rollins*

Rebecca Guy*

Walter Justus

Meredith Myers

Greg Myers

Kristen Yates

** Denotes Factor Club Awardee (an individual raising over \$500)*

Thank you to all of the Team Captains for all of their hard work:

Kyla Krieger (*Team Sir Huxley*)

McKenzie Rollins (*The Red Comets*)

Walter Justus (*Justus For All*)

Rebecca Guy (*9 Guy's Family & Friends Team*)

Joe Rex (*The Rex Factor*)

Zach Walker (*IX Walkers*)

Brittany Payton (*Team Spencer (Phelps)*)

Russ Brenneman (*Team Big Sky*)

Stephanie Shea (*The Koda-nauts*)

Leo Tellez (*B-Active*)

Laura Visoso (*The Zapatas*)

Julia Barnett (*Team Liam!*)

vWD Education & Appreciation Month

In our inaugural education series dedicated to the von Willebrand Disease (vWD) community, we hosted three successful educational events during the month of October. Throughout the three events we had over a dozen affected families participate. During these events our community members were able to learn more about vWD, connect with others in the community, and engage in important dialogue that provided support and understanding.

We would like to thank CSL Behring, Octapharma, and Takeda for making these programs possible.

Women's Group

Women in our community were able to connect again during our Women's Group event in November. The women were able connect on a deep and personal level while being engaged in a dialogue led by Kelly Gonzalez.

Thank you to Octapharma for supporting this event

Men's Group

During the middle of November, men in the community got together on a zoom call for some education and fun. It was nice to have another men's group event- it was long overdue, since we last met earlier this year in January. During our time, we played two rounds of Code names—a fun, interactive game that was new to most of us.

Thank you to Octapharma for supporting this event

New Partnership

and opportunity for our community members!



This partnership allows us to support counseling session for affected members and their caregivers in our community.

More information and to apply go here: www.idahoblood.org/support



EXPERIENCE MATTERS

BeneFix is FDA approved for once-weekly prophylaxis and on-demand use to fit your dosing needs—from the only recombinant factor IX supporting individuals with hemophilia B for more than 20 years.*

Not actual patients.



More than 20 years* of experience—the first recombinant treatment for individuals with hemophilia B



Dosing options to meet your needs—for once-weekly prophylaxis and on-demand use



Designed with viral safety in mind. More than 150 quality control tests are done on each batch of BeneFix



The convenience of the BeneFix Rapid Reconstitution (R2) Kit with a range of vial sizes



What Is BeneFix?

BeneFix, Coagulation Factor IX (Recombinant), is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

ASK YOUR DOCTOR WHICH BENEFIX[®] DOSING OPTIONS MAY BE RIGHT FOR YOU

Important Safety Information

- BeneFix is contraindicated in patients who have manifested life-threatening, immediate hypersensitivity reactions, including anaphylaxis, to the product or its components, including hamster protein.
- Call your health care provider right away if your bleeding is not controlled after using BeneFix.
- Allergic reactions may occur with BeneFix. Call your health care provider or get emergency treatment right away if you have any of the following symptoms: wheezing, difficulty breathing, chest tightness, your lips and gums turning blue, fast heartbeat, facial swelling, faintness, rash, or hives.
- Your body can make antibodies, called "inhibitors," which may stop BeneFix from working properly.
- If you have risk factors for developing blood clots, such as a venous catheter through which BeneFix is given by continuous infusion, BeneFix may increase the risk of abnormal blood clots. The safety and efficacy of BeneFix administration by continuous infusion have not been established.
- Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness, and rash.

Please see the Brief Summary for BeneFix on the next page.



BeneFix[®]
Coagulation Factor IX (Recombinant)
Room Temperature Storage

*BeneFix was approved February 11, 1997.

R_x only

Brief Summary

See package insert for full Prescribing Information. This product's label may have been updated. For further product information and current package insert, please visit www.Pfizer.com or call our medical communications department toll-free at 1-800-438-1985.

Please read this Patient Information carefully before using BeneFix and each time you get a refill. There may be new information. This brief summary does not take the place of talking with your doctor about your medical problems or your treatment.

What is BeneFix?

BeneFix is an injectable medicine that is used to help control and prevent bleeding in people with hemophilia B. Hemophilia B is also called congenital factor IX deficiency or Christmas disease. Your doctor might also give you BeneFix before surgical procedures.

BeneFix is **NOT** used to treat hemophilia A.

What should I tell my doctor before using BeneFix?

Tell your doctor and pharmacist about all of the medicines you take, including all prescription and non-prescription medicines, such as over-the-counter medicines, supplements, or herbal medicines.

Tell your doctor about all of your medical conditions, including if you:

- have any allergies, including allergies to hamsters.
- are pregnant or planning to become pregnant. It is not known if BeneFix may harm your unborn baby.
- are breastfeeding. It is not known if BeneFix passes into the milk and if it can harm your baby.

How should I infuse BeneFix?

The initial administrations of BeneFix should be administered under proper medical supervision, where proper medical care for severe allergic reactions could be provided.

See the step-by-step instructions for infusing in the complete patient labeling.

You should always follow the specific instructions given by your doctor. If you are unsure of the procedures, please call your doctor or pharmacist before using.

Call your doctor right away if bleeding is not controlled after using BeneFix.

Your doctor will prescribe the dose that you should take. Your doctor may need to test your blood from time to time. BeneFix should not be administered by continuous infusion.

What if I take too much BeneFix?

Call your doctor if you take too much BeneFix.

What are the possible side effects of BeneFix?

Allergic reactions may occur with BeneFix. Call your doctor or get emergency treatment right away if you have any of the following symptoms:

wheezing	fast heartbeat
difficulty breathing	swelling of the face
chest tightness	faintness
turning blue (look at lips and gums)	rash
	hives

Your body can also make antibodies, called "inhibitors," against BeneFix, which may stop BeneFix from working properly.

Some common side effects of BeneFix are fever, cough, nausea, injection site reaction, injection site pain, headache, dizziness and rash.

BeneFix may increase the risk of thromboembolism (abnormal blood clots) in your body if you have risk factors for developing blood clots, including an indwelling venous catheter through which BeneFix is given by continuous infusion. There have been reports of severe blood clotting events, including life-threatening blood clots in critically ill neonates, while receiving continuous-infusion BeneFix through a central venous catheter. The safety and efficacy of BeneFix administration by continuous infusion have not been established.

These are not all the possible side effects of BeneFix.

Tell your doctor about any side effect that bothers you or that does not go away.

How should I store BeneFix?

DO NOT FREEZE the BeneFix kit. The BeneFix kit can be stored at room temperature (below 86°F) or under refrigeration. Throw away any unused BeneFix and diluent after the expiration date indicated on the label.

Freezing should be avoided to prevent damage to the pre-filled diluent syringe.

BeneFix does not contain a preservative. After reconstituting BeneFix, you can store it at room temperature for up to 3 hours. If you have not used it in 3 hours, throw it away.

Do not use BeneFix if the reconstituted solution is not clear and colorless.

What else should I know about BeneFix?

Medicines are sometimes prescribed for purposes other than those listed here. Do not use BeneFix for a condition for which it was not prescribed. Do not share BeneFix with other people, even if they have the same symptoms that you have.

If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about BeneFix that was written for healthcare professionals.

This brief summary is based on BeneFix® [Coagulation Factor IX (Recombinant)] Prescribing Information LAB-0464-12.0, revised June 2020.



Community
Voices in
Research

What is CVR?

Community Voices in Research (CVR) formally known as *MyBDC*, is a community-powered registry but most importantly it is a partnership between the bleeding disorders community *and* NHF. When enrolling in CVR you are adding *your* voice and *your* experience which in turn helps to determine the direction of research for our community!

The Power of Data

Your voice turns into deidentified aggregated data which provides necessary useful information! For example; collected data from your local chapter community can highlight the possible need for additional women's programming and provide the required data to apply for grants to fulfill that need.

Call to Action!

Have you registered for CVR **and** taken your baseline survey already? If not, we are talking to *you*, your Idaho Chapter needs *you*! When you enroll in CVR **and** complete your baseline survey you are providing immediate valuable deidentified aggregated data for your community!

Enroll Now!

- **Step 1: Take enrollment survey** (2 minutes). Answer a few questions about you and how bleeding disorders affect you.
- **Step 2: Take baseline survey** (20-30 minutes) by following the link sent to your email. It will ask you more detailed questions about living with a bleeding disorder. You don't have to complete it all in one sitting.
- **Step 3: Access your CVR Dashboard.** Now you have access to everything CVR has to offer!

Ready to get started?

www.hemophilia.org/cvr





YOUR HTC

The Idaho Hemophilia Treatment Center (HTC) is part of the St. Luke's Health System, located in Boise. A dedicated staff of skilled caregivers provide treatment and extensive support including: annual checkups, counseling, disease specialists, lab tests, and education for patients with hemophilia, von Willebrand disease, and other blood disorders.

Staff

HTC Coordinator and Pediatric Nurse Practitioner

Kara Gardner, RN, PNP-BC

Hematologists/Oncologists

Nicolas Camilo, MD

Eugenia Chang, MD

Matthew Hansen, MD

Nathan Meeker, MD

Infectious Disease

Thomas Rand, MD, PhD

Family Nurse Practitioner

Marni Allen, FNP-BC

Social Worker

Diane Bartlett

Physical Therapist

Kay Craig

Career Counselor

Colin Car, MSED

Nutritionist

Amy Mercer

Genetic Counselor

Christina Ikard

Address

100 E. Idaho St.

Boise, ID 83712

For information and appointments

208.381.2782

or Toll Free

1-800-845-4624

Holiday Party

We brought back the Holiday Party this year—and it was a hit! We had 18 families attend our virtual party—thank you to all those who participated. We all learned our reindeer, elf, and snowman name; played a game; and learned more about each others' holiday traditions.


Oh yeah, Santa even stopped by to say hi and remind us about the goodies he dropped off earlier. Seeing all of the smiling faces—children and adults—during the party was a great way to wind down our 2020 programming.



Education Event-Genentech

During the month of December, our community was fortunate enough to have two educational sessions hosted by Genentech. During these sessions, our families in attendance watched a "Challenge Accepted" video and were able to discuss the episode content after. During the discussion we were challenged to reach out to a fellow community member and check-in to see how they are doing. This was a great idea to keep us connected, giving the current circumstances.

Thank you, Genentech, for supporting these two fun educational events!



“We're Listening”

PLEASE CONSIDER FILLING OUT OUR CHAPTER NEEDS ASSESSMENT SO WE CAN DEVELOP OUR PROGRAMMING BASED ON YOUR FEEDBACK.

WWW.IDAHOBLOOD.ORG/SURVEY

COMMUNITY ASSISTANCE FUNDS AVAILABLE

We are aware of the huge cost of factor and the care of those with bleeding disorders.

We want to remind you that the Chapter can help with the expense of utilities, doctors' bills, travel and other household bills up to \$500 per year. If you need help with immediate expenses, please call or email Michael at the Chapter office and ask for a Community Assistance Project form.

208-344-4476
mkrieger@hemophilia.org

Jivi[®] Extension Study

Explore the study design and see the safety and efficacy data from patients who were part of the study.

► Dive in at [JiviExtensionStudy.com](https://www.JiviExtensionStudy.com)

To me, it's personal.

As a Community Relations and Education Manager for Sanofi Genzyme, I'm here to help provide support and resources for you and the Idaho hemophilia community.

Danielle Macomber
CoRe Manager for Idaho

Let's connect.

Call, text, video chat: 253-331-5434

Email: danielle.macomber@sanofi.com

Facebook: @HemophiliaCoRes

SANOFI GENZYME 

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HEM-US-7108 3/20



TEEN PROGRAM

Calling all Teens

We want to hear from you. We are working to get a regular schedule of activities. What do you like to do? What activities would you like to try? What outdoor skills do you want to learn? We are looking for ideas and suggestions.

We also need teens to help plan and develop the program. Involvement looks great on a scholarship or college application, or a resume.

Please contact the chapter office with your ideas or your desire to help.

208-344-4476

Find us on our new *facebook* group and join the group.
Teens With Idaho Chapter of NHF

WE ARE LOOKING FOR INDIVIDUALS TO MAKE A DIFFERENCE

in our community and who would like to be on a committee.

Help is needed on the following:

**CAMP
SOCIAL MEDIA
TEEN PROGRAM
VICTORY FOR WOMEN
MEN'S GROUP
UNITE WALK**

If you can help, please contact the Chapter office, today!

208-344-4476

or idaho@hemophilia.org

DID YOU KNOW?

Did you know that NHF Idaho Chapter has a program that makes it easy to donate a little every month to the Chapter?

Go to idahoblood.org, click on **DONATE NOW**, set up a reoccurring monthly donation account. You can set it up for any amount: \$10 a month is \$120 a year—that helps send a child to camp.

Share the news. If we all give a little we can help our Chapter to grow.

OWN A SMALL BUSINESS?

Members of the NHF Idaho Chapter community are invited to submit advertisements for their business to appear in our Newsletter,

FREE

Ads will be subject to space availability and approval by the staff.
Ads should be submitted in a ready to print digital format.

Acceptable files are JPG (150dpi, minimum) or PDF.

Size of ad must be 3¼" w x 3⅜" h. For additional information call the Chapter office,

208-344-4476

WE NEED YOUR PHOTOS!

We are putting together a 2021 Calendar again, but need your help with photos! Do you have family or group photos of community members from this year to share? Please send them to idaho@hemophilia.org to be featured in our calendar.



The NHF Idaho Chapter NEWSLETTER is published quarterly in Boise, ID. For information, questions, to submit articles or advertising for the Newsletter please contact,

Michael Krieger 208-490-2596 or
mkrieger@hemophilia.org.

The information contained in the NHF Idaho Newsletter is provided for your general information only. NHF Idaho does not give medical advice or engage in the practice of medicine. NHF Idaho, under no circumstances, recommends particular treatments or endorses products for specific individuals and in all cases recommends that you consult your physician or Hemophilia Treatment Center before pursuing any course of treatment.



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